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PII: \$1499-2671(23)00126-0

DOI: https://doi.org/10.1016/j.jcjd.2023.05.005

Reference: JCJD 1670

To appear in: Canadian Journal of Diabetes

Received Date: 4 March 2023
Revised Date: 24 April 2023
Accepted Date: 9 May 2023

Please cite this article as: Niyyati S, Fung A, Zhang Q, Ng C, Amed S, Bone JN, Ziabakhsh S, Hursh BE, Patient perceptions of telehealth for pediatric type 1 diabetes during the COVID-19 pandemic: a follow-up study *Canadian Journal of Diabetes* (2023), doi: https://doi.org/10.1016/j.jcjd.2023.05.005.

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Patient perceptions of telehealth for pediatric type 1 diabetes during the COVID-19 pandemic: a follow-up study

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Key Messages:

- 1. At the onset of the COVID-19 pandemic, initial studies showed good usability and satisfaction for telehealth in pediatric diabetes care.
- 2. We now show that the desire by families for future telehealth care has strengthened significantly from early to later in the pandemic.

3. Nearly all families would like their future diabetes care to include a combination of in-person and

multidisciplinary telehealth visits.

Keywords: Diabetes mellitus, type 1; Child; Adolescent; Telemedicine; COVID-19

Acknowledgements:

This study was supported by a 2021 Canucks for Kids Fund Diabetes Legacy Grant from the Canucks for

Kids Fund Diabetes Laboratories at the BC Children's Hospital Research Institute. This research did not

receive any other specific grants from funding agencies in the public, commercial, or not-for-profit

sectors. We also thank the families who participated in the survey, and those who participated in survey

review and development.

Author Contributions:

S.N., A.F., Q.Z., J.B., S.Z., and B.H. designed the study. C.N. and S.A. provided BC P.D.R. data linkage.

S.N., Q.Z., J.B., S.Z., and B.H analyzed the data. S.N. and B.H. produced the first draft of the manuscript

and all authors were involved in review and production of the final manuscript. All authors have read and

approved the final manuscript.

Author Disclosures:

The authors report no conflicts of interest that could impact the integrity of this work.

Word Counts:

Abstract: 249

Body: 4000

Number of tables: 3

Number of figures: 1

Abstract

Background

There was rapid uptake of pediatric diabetes telehealth at the onset of the COVID-19 pandemic and initial studies demonstrated good usability and satisfaction.

Objectives

As exposure to telehealth continued to increase during the pandemic, we aimed to determine *changes* in telehealth usability and *changes* in future preferences for telehealth care.

Methods

A telehealth questionnaire was administered early in the pandemic and again more than one year later. Survey data was linked with a clinical data registry. A multivariable proportional odds logistic mixed effects model was performed to assess the association between exposure to telehealth and outcome of future preference for telehealth. Multivariable linear mixed effects models were used to examine associations between exposure to early and later pandemic periods and the outcome of usability scores.

Results

Survey response rate was 40%, with 87 early and 168 later period participants. Virtual visits increased from 46% to 92% of all telehealth visits. Virtual visits improved in 'ease of use' (p=0.0013) and 'satisfaction' (p=0.045); there were no improvements in telephone visits. The odds of indicating higher preference for more future telehealth visits was 5.1 times higher in the later pandemic group (p=0.0298). 80% of participants would like their future care to include telehealth visits.

Conclusion

At our tertiary diabetes centre, families' desire for future telehealth care has increased during this oneyear period of additional telehealth exposure, and virtual care has now become the preferred option. This study provides important family perspectives that can help guide development of future diabetes clinical care.

Introduction

Pediatric type 1 diabetes (T1D) requires intensive daily medical management and regular diabetes clinical visits [1]. Prior to the COVID-19 pandemic, the diabetes team at British Columbia Children's Hospital (BCCH) held approximately 1400 'in-person' diabetes ambulatory visits each year. Telehealth accounted for less than 5% of all visits and this service was mainly provided to patients and their families who faced difficulties traveling to the hospital, including long-distance and costly travel [2]. This was consistent with the low prevalence of pediatric diabetes telehealth care world-wide prior to the pandemic [3].

During the early stages of the COVID-19 pandemic, and in line with provincial health mandates, the diabetes team rapidly shifted to performing 100% of routine visits by video or telephone. This increase in telehealth visits for diabetes care was experienced in many areas around the world [3, 4]. However, despite the rapid uptake of video and telephone care in the setting of the COVID-19 pandemic, there was limited evidence for the effectiveness and quality of these services for pediatric T1D.

There has now been the opportunity for many diabetes patients and clinicians to experience telehealth, while at the same time the use of telehealth in diabetes care has become more feasible due to recent advances in diabetes technology, availability of telecommunication tools, and improved healthcare infrastructure. In line with this, recent studies have explored the rapidly expanding field of telehealth in diabetes care. Telehealth for diabetes has been noted to have a positive impact on glucose management, adherence, and financial impact on families [5-8]. Furthermore, it has generally been noted to have high satisfaction rates [9, 10]. Telehealth has also been found to be equally effective in providing diabetes training sessions as inperson training [11]. Prior to the onset of the COVID-19 pandemic, diabetes telehealth visits in our division were held using hospital-based telehealth equipment, where both the provider and patient were in a healthcare setting using healthcare grade video and audio technology. In the context of this study period, however, we use the term telehealth to refer to the provision of remote medical care using video and/or audio technology, with the patient able to choose the location of their visit using widely available internet-based video applications or by telephone.

At BCCH, an initial survey was carried out using the Telehealth Usability Questionnaire (TUQ) for virtual and telephone visits for routine diabetes care during the first 3 months of the pandemic (March 25 to May 27, 2020). That study demonstrated impressive telehealth usability, encompassing the areas of usefulness, ease of use, interface quality, interaction quality, reliability, and satisfaction and future use [2, 12]. In that initial study, 72% of families hoped to continue telehealth as part of their future care following the pandemic

[2]. While most participants preferred to continue to have telehealth visits in the future, there was a significant proportion of families (24%) who preferred all future care to be in-person [2].

As exposure to telehealth continues to increase, one area of specific interest is how the experience of telehealth is changing for families *during* the pandemic. With both providers and families becoming more acquainted with telehealth at BCCH, we now set out to determine any *changes* in family perceptions of telehealth usability and their future preferences for telehealth care.

Methods

Context

BCCH is the sole tertiary children's hospital in British Columbia (BC), Canada. The multidisciplinary diabetes team serves approximately 900 children with diabetes from across BC. Prior to the COVID-19 pandemic, patients would routinely have 1 to 3 in-person visits annually. As a result of the pandemic, all routine diabetes visits were switched to telehealth starting March 25, 2020, and this requirement for telehealth visits for all non-urgent patient encounters continued throughout the study period. To conduct telehealth visits, patient families were contacted by our administrative staff and offered the option to select either telephone visit (audio only) or virtual visit (video and audio). All visits were scheduled to be 30 minutes in length. Prior to each telehealth visit, a diabetes nurse educator contacted the family and encouraged them to send in blood glucose and insulin dose information by email and to upload any diabetes technology data (i.e. pump and/or continuous glucose monitor (CGM) data).

Study Design

We utilized a telehealth questionnaire administered at two time periods. Early in the pandemic (the "early pandemic period"), all families who had a telephone or virtual diabetes visit between March 25 and May 27, 2020 were invited to partake in the survey, with survey data collected from May 28 to June 9, 2020. Subsequently, more than one year later (the "later pandemic period"), all families who had a telephone or virtual diabetes visit between May 1 and November 6, 2021, were invited to complete the survey, with survey data collected from November 7 to December 1, 2021. In each timeframe, a consent form and letter of introduction were emailed to participants with a link to complete the survey online via the Research Electronic Data Capture (REDCap) online database platform. The survey was completed by the pediatric patient, a parent/caregiver, or both. Families who had visits at both time periods were invited to both surveys.

The majority of BCCH diabetes patients participate in the BC Pediatric Diabetes Registry (the BC-PDR) [13]. The BC-PDR includes de-identified clinical data such as patient demographics, laboratory results, diabetes technology use, and diabetes management obtained from patient medical records for the purpose of supporting quality improvement research. Participating families were asked for permission to link their survey data with their patient data from the BC-PDR. Families participating in the current study were assigned a unique identification code for privacy and confidentiality purposes.

Questionnaire

The questionnaire consisted of the Telehealth Usability Questionnaire (TUQ), modified to the current context of telephone and virtual visits. Additional questions were also developed by the healthcare team at the BCCH Diabetes Clinic, to assess visit characteristics and family preferences regarding telehealth care during the pandemic and beyond. The TUQ is a validated tool designed to assess the delivery of telehealth care, focusing on 6 domains, including usefulness, ease of use, interface quality, interaction quality, reliability, and satisfaction and future use. The TUQ can be tailored to address telehealth systems in different settings. It has strong content validity, reliability, and has been noted to be a solid, robust and versatile measure [12]. There were no alterations made to questions in intention or meaning. A four-point Likert scale was used, with response categories of "Not at all/Partly/Quite a bit/Completely", consistent with the scale used in the pan-Canadian patient survey [14].

The additional questions developed for this study assessed visit characteristics and preferences for future care. These questions were analyzed separately from the TUQ questions. These questions were designed by an interdisciplinary team of pediatric endocrinologists, diabetes nurse- and dietitian-educators, endocrinology trainees and diabetes administrative staff; and these team members pilot tested the entire survey. In addition to healthcare team members, some of whom have T1D, the survey was also piloted with two young adults with T1D who do not work in healthcare to assess comprehension and ease of completion. Their comments resulted in changes to survey language resulting in increased clarity and readability. Following the first data collection during the early pandemic period, the survey questions were reassessed by the diabetes team and updated with additional questions using participant and practitioner feedback. There were two narrative (open-ended) questions added to the second (later pandemic) questionnaire, with the aim of capturing in-depth patient feedback about their experience with diabetes care via telehealth visits: "What did you find most helpful about having your care at the diabetes clinic done by telephone or virtually?" and "What didn't you like about having your care at the diabetes clinic done by telephone or virtually?". The full questionnaire is included as Appendix A1.

Quantitative Data Analysis

Outcome measures

Outcomes included usability scores, which consisted of scores from each of six domains and the sum of these scores (overall score). In each domain, the score was determined by the median of scores from questions included in the domain. Therefore, the domain scores could range from 1 to 4, while the overall score could range from 6 to 24. The outcome of preference for future virtual visits was also assessed, which included 3-level responses: "Yes (telehealth for all future visits)/Some (telehealth for some future visits)/No (no future telehealth visits)".

Exposure to telehealth

The key explanatory variable was level of exposure to telehealth, defined by pandemic period, including "early pandemic" (early exposure) (March-May, 2020), and "later pandemic" (marked by more exposure to telehealth) (May-November, 2021).

Effect modifier and confounders

We treated the type of telehealth (phone vs. virtual) as a possible effect modifier to evaluate possible differential effect. Patient age, sex, time since diagnosis, pump use, CGM use, HbA1c, and distance from BCCH were included in models as potential confounders.

Statistical methods

Descriptive statistics were used to summarize the characteristics and questionnaire scores of the study sample. To examine associations between exposure to early and later pandemic periods and the outcome of usability scores, multivariable linear mixed effects models were conducted. These models included interactions to estimate possible effect modification by telehealth approach. We used linear models as results from these have been shown to be robust when applied to Likert data (which is not technically continuous) [15]. In a sensitivity analysis to assess robustness of results to model specification we instead applied a multivariable proportional odds logistic mixed effects models to this data. Additionally, to assess the association between exposure to telehealth (early and later pandemic periods) and outcome of patient future preference, a multivariable proportional odds logistic mixed effects model was conducted with effect modification by telehealth approach. All models were adjusted for confounders listed above and included random effects for repeated measures from the same participants.

Results were summarized using adjusted mean differences (linear models) and odds ratios (logistic models), with corresponding 95% confidence intervals. The marginal predicted effects were also displayed

graphically (i.e. the adjusted figure demonstrating marginal estimated outcomes in each domain, period, and telehealth approach, at most common covariate values).

All analyses were conducted by using SAS 9.4 (SAS Institute Inc, Cary, NC). The current study was mainly exploratory, and no adjustment for multiple comparisons was performed.

Qualitative Data Analysis

Qualitative data captured via open-ended questions were thematically analyzed using inductive technique [16]. Data was reviewed by three authors and a coding scheme was developed by consensus based on the themes presented. Two independent coders reviewed and assigned codes to each comment. Afterwards, the two coders compared their coding, and differences were discussed until consensus was reached. Frequency counts were calculated, and some codes were combined to create broader themes or overarching categories.

Research Ethics

This study was conducted for quality improvement and monitoring and, therefore, did not fall under the scope of the Research Ethics Board, as per the University of British Columbia Guidance notes, Article 4.4.1 and Tri-Council Policy Statement 2 (TCPS2) Article 2.5 [17, 18]. Approval for the administration of this quality improvement survey was granted by the Research Privacy Advisor (Provincial Health Services Authority), which is the requirement for quality improvement studies at our institution. Hence, data collection occurred in accordance with the agency's privacy laws. Consent was gathered at the time of survey administration, and participants were informed that they could withdraw their consent at any time. This project meets A pRoject Ethics Community Consensus Initiative (ARECCI) Ethics Screening Tool criteria for Quality Improvement and Evaluation projects [19].

Results

Survey Response

The overall response rate was 40%. For the early pandemic survey, amongst the 301 eligible patient families, 141 responded to the survey, resulting in a 47% response rate. Eighty-seven had previously consented to be a part of the BC-PDR and were included in our analysis. For the later pandemic survey, out of 733 eligible patient families, 273 completed the survey, resulting in a 37% response rate. 168 had previously consented to be a part of the BC-PDR and were included in our analysis. Twenty-seven patient families participated in both the early and later pandemic questionnaires.

Characteristics of survey respondents with linked clinical data are provided (Table 1). Early and later pandemic groups were similar in age, time since diagnosis, HbA1c, sex, type of diabetes, and CGM use. The early group had a lower proportion of multiple daily injection routines (33% vs. 45%) and a higher proportion of pump users (51% vs. 44%). The overall characteristics of the study participants were similar to the larger group of patients in the BC-PDR (Table 1).

The Visit

There was a dramatic shift toward using virtual visits compared to telephone visits between the early and later pandemic periods, as virtual increased from 46% to 92% of all telehealth visits (Table 1). Along with the transition to virtual visits, there was also more participation of the child or adolescent in later pandemic period telehealth visits (81% to 92%). While early pandemic visits mainly included a single provider (only 36% had more than one provider), the later pandemic period transitioned to more multidisciplinary team visits (80% had more than one provider).

Usability

Across the TUQ components of usefulness, ease of use and learnability, interface quality, interaction quality, and satisfaction and future use, all had median scores for both types of visits in early and later periods of "quite a bit (3)" or "completely (4)", while the score for reliability for both groups in both time frames was "partly (2)". It is noteworthy that median scores for ease of use and learnability, interface quality, and overall usability increased from 3 to 4 for virtual visits from early to later pandemic periods while telephone visits did not change. The scores for individual questions and domains are included in Appendix A2.

In assessing the adjusted associations of usability scores with pandemic periods, stratified by telephone and virtual visits, while controlling for confounders, over time our virtual visits had an improvement in 'ease of use' [mean difference (95% CI) 0.39 (0.17, 0.61), p=0.0013] and 'satisfaction' [0.28 (0.01, 0.55), p=0.045], and a possible improvement in 'interface quality' [0.24 (-0.04, 0.52), p=0.0894], 'reliability' [0.030 (-0.04, 0.64), p=0.0804] and 'overall usability score' [0.25 (-0.03, 0.53), p=0.0728], although confidence intervals for these outcomes included small decreases. There was no similar improvement in telephone visits (Table 2, Figure 1). The sensitivity analyses also showed a consistent pattern and trend (Appendix A3).

Patient Narrative Commentary

Participants in the later pandemic questionnaire provided narrative comments about what was "most helpful" and what they "didn't like" about their recent telehealth visit. Of 168 participants, there were 129 "most helpful" and 127 "didn't like" responses provided. Table 3 highlights the major themes that emerged from the qualitative analysis. There are many patient-centered benefits from telehealth care such as time and cost saving, less work/school interruptions, and personal convenience. However, many families also had reservations about giving up the benefits of in-person interactions and in-person examinations. A small but important group also struggled with the technology associated with these visits. A selection of narrative comments is included in Appendix A4.

Preferences for Future Telephone and Virtual Diabetes Care

In examining the adjusted associations between user preference for future telehealth visits and pandemic period, when stratified by telehealth approach and controlling the confounders, the odds of indicating higher preference for more future virtual visits in the later pandemic group was 5.1 times higher than that in the early pandemic group (OR: 5.10, 95%CI: 1.02, 21.70, p=0.0298) (Table 2). Many families would like telehealth visits to include multiple team members, and this desire increased between the early and later pandemic periods (72% to 80%).

Optimal Frequency of Telehealth and In-person Visits

Overall, 80% of participants would like their future care to include telehealth visits in place of some or all in-person visits after the pandemic. The most desired future combinations of in-person and telehealth appointments were 2 in-person and 2 telehealth visits per year (28%), followed by 1 in-person 3 telehealth visits per year (17%), with a range of responses from 0 to 4 for each type of visit.

Discussion

To our knowledge this is the first pediatric study to evaluate the evolving preferences for pediatric telehealth care during the COVID-19 pandemic. Looking within this time of transition to telehealth care, between the early and later pandemic periods there was a dramatic shift toward virtual visits, and away from telephone visits. Compared with earlier in the pandemic, the usability of virtual visits improved over time in several key areas, and the visits became more frequently multidisciplinary and had improved engagement of youth as well. It is most interesting that over this time, families' desire for future telehealth has strengthened, as the odds of an increasing level of desire for telehealth for some or all future care increased significantly from early to later in the pandemic. This finding has direct impact on clinical planning, as it is a strong signal from families that not only do they wish for a future including telehealth care, but in fact their desire for telehealth care is increasing over time.

While there are no prior studies in pediatric T1D care regarding change in future preference for telehealth care, a global survey distributed primarily to adults with T1D through social media found a decrease in future preference for telehealth visits throughout the pandemic [9]. Making a direct comparison between these two studies is problematic as telehealth is defined and practiced differently depending on the context and the sampling methods of the studies are very different. Some additional possible reasons for the discrepancy include differing geographic locations, different levels of service provided, and differences in needs between pediatric and adult patients. Both studies, however, found excellent satisfaction with telehealth visits over time during the pandemic. High satisfaction has also been documented in several studies in pediatric subspecialty patients during the COVID-19 pandemic [20-23], as well as in a study of children and young adults with T1D [10].

Prior to the COVID-19 pandemic, the provision of diabetes care at our tertiary hospital was very provider-centric: families travelled from around the province to have visits at our centre, and appointment times were relatively inflexible. What started as a mandated switch to telehealth early in the pandemic has now led to an opportunity to redefine our care in a more patient-centered way. Some of the main tenets of patient-centered care can be realized through inclusion of telehealth such as increasing accessibility of care, providing access for remote family members to join visits, and respecting both family preferences and socioeconomic conditions [24]. In this way, the inclusion of telehealth in future care has the ability to impact three of the quintuple aims of healthcare improvement: experience, cost, and equity [25]. The other two, impact on outcomes and staff wellbeing, are ripe areas for further research in pediatric T1D.

In terms of patient experience, the usability of virtual visits, but not telephone visits, increased from early to later pandemic periods. Statistically significant changes in ease of use and satisfaction, along with trends toward significance in other areas, show how dynamic the adaptation to virtual care has been at our centre. This is likely related to both family and clinic factors, including increased family involvement in virtual communication in many aspects of life, increased healthcare provider experience in providing virtual care, and healthcare system investment in hardware technologies (e.g. headsets and cameras) and virtual care software. The improved experience with virtual care at our centre can only serve to reinforce its potential as a tool for modern health care. In contrast, the use of telephone visits decreased dramatically at our centre, and there was no change over time in the families' experience with telephone visits for those who did participate in them.

Characteristics of telehealth visits at our centre changed from early to later pandemic periods. When given the choice between virtual or telephone visits, the preference for virtual visits increased dramatically over the pandemic, with a near-total shift toward virtual care visits later in the pandemic (from 46% to 92% of all telehealth visits), and this is consistent with a prior study focusing on adults with T1D [9]. There was also more inclusion of children and adolescents in our visits in the later pandemic period, which may be explained by better facilitation of multiple participant visits with virtual care as well as children and adolescents adapting to virtual technology in school, extra-curricular activities, and work as the pandemic progressed. This is consistent with previous findings that have demonstrated virtual visits allow both patients and families to express their medical problems, speak easily with the diabetes team, and feel comfortable [10]. Compared to early in the pandemic, our centre also carried out many more multidisciplinary virtual visits later in the pandemic, and in turn families in the later pandemic period requested even more attendance of the multidisciplinary team going forward compared to family preferences from the early pandemic period. The increasing preference for multidisciplinary virtual care may be explained by the efficiency and additional support it provides families during each visit.

The narrative comments provide a personal perspective regarding telehealth diabetes care. Many families provided positive feedback regarding improved access to care related to time and cost savings, less work and school interruptions, and personal convenience. A hybrid model is preferred by most, and this was highlighted here in reservations expressed about completely giving up the benefits of in-person care. Some in person connection allows for physical checkups, coordination of screening lab work, and improved communication and relationship building. Further supporting a hybrid model of care, a recent study found that diabetes clinic anthropometric measurements and screening laboratory investigations decreased dramatically at one year into the pandemic in the setting of virtual-only care [26]. The themes that emerged in our study are also consistent with a prior study of the perspectives of youth on virtual appointments during the pandemic. The authors found overall positive feelings about virtual care as it contributes to time saving, ease of access, continuity of care, and the convenience of participating from the comfort of one's own home, while acknowledging limitations of lack of physical examinations and inability to complete bloodwork and imaging tests [27].

In terms of strengths, this study captured the perspectives of many families during this time of transition to telehealth care. The response rate was reasonably high for a survey study and the study population was representative of our overall clinic population. Another strength is the linkage of survey data with the BC-PDR, enabling a comprehensive picture of our study population. A limitation of our study is the potential for non-responder bias as study participants may be systematically different than those who chose not to participate. Furthermore, experiences of diverse populations with telehealth need to be considered, for

example, those with English as second language, Indigenous patients/families, and families experiencing multiple barriers; however, those groups may have experienced barriers in survey participation. It is interesting to note that despite higher overall participant numbers in the later period, the later pandemic survey had a lower response rate. One possible interpretation is that as the pandemic continued there may have been less interest in participating in surveys about the pandemic and/or telehealth. The rate of participation of families in both surveys is again lower than would be expected when considering the likelihood that a family would have had a clinic visit in both the early and later timeframes. Perhaps, similarly, this is related to fatigue in participating in pandemic-related surveys, especially for families who already contributed to an initial survey. It is possible that there are differences between those who did or did not choose to respond later on in the pandemic, and this could introduce non-responder bias. Additionally, while the TUQ is a tool well suited for assessment of telehealth in a variety of settings, to our knowledge it has not been validated to detect change over time. Another limitation is that this study did not capture the perspectives of the healthcare professionals who were part of these visits.

Brief Conclusion

The landscape of pediatric diabetes care is changing rapidly, and it is important to assess the impacts of these changes on the children and families we serve. Initial data has shown that telehealth care has been well received, and now here we highlight that, at our tertiary centre, virtual care has expanded dynamically in both proportion and quality during the pandemic and that families' desire for future telehealth care has increased. The results of this study are helpful in planning future care delivery at our centre, and continued evaluation of telehealth is an important key to optimizing our delivery of patient-centered care. Efforts to include healthcare provider perspectives and to evaluate health outcome measures will be essential next steps. Future research should also address optimal frequency of telehealth visits to optimize patient and provider satisfaction without negatively impacting patient outcomes.

Acknowledgements

This study was supported by a 2021 Canucks for Kids Fund Diabetes Legacy Grant from the Canucks for Kids Fund Diabetes Laboratories at the BC Children's Hospital Research Institute. This research did not receive any other specific grants from funding agencies in the public, commercial, or not-for-profit sectors. We also thank the families who participated in the survey, and those who participated in survey review and development.

Author Contributions

S.N., A.F., Q.Z., J.B., S.Z., and B.H., designed the study. C.N. and S.A. provided BC P.D.R. data linkage. S.N., Q.Z., J.B., S.Z. and B.H analyzed the data. S.N. and B.H. produced the first draft of the manuscript and all authors were involved in review and production of the final manuscript. All authors have read and approved the final manuscript.

Author Disclosures

The authors report no conflicts of interest that could impact the integrity of this work.

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Table 1. Characteristics of survey participants and all patients enrolled in the BC Pediatric Diabetes Registry

Survey Participants						
	2020	2021	Diabetes			
Characteristics	Early	Later	Registry			
	Pandemic	Pandemic	Patients			
	(n=87)	(n=168)	(n=614)			
Age (years), mean (SD)	12.8 (4.3)	12.1 (4.1)	14.0 (4.3)			
Time since diagnosis, mean (SD)	6.7 (4.3)	6.8 (4.1)	6.6 (4.3)			
Most recent HbA1c, mean (SD)	7.9 (1.8)	8.0 (1.7)	8.1 (1.7)			
Sex, n (%)						
Female	37 (43)	72 (43)	280 (46)			
Type of diabetes, n (%)						
Type 1 diabetes	85 (98)	161 (96)	578 (94)			
Type 2 diabetes	2 (2)	3 (2)	11 (2)			
Other	0	4 † (2)	25 ‡ (4)			
Distance from centre (km), n (%)						
<10	24 (28)	64 (38)	-			
10 - 24.9	28 (32)	52 (31)	-			
25 - 99.9	24 (28)	24 (14)	-			
100 - 200	2 (2)	15 (9)	-			
>200	9 (10)	13 (8)	-			
Currently using CGM, n (%)	49 (56)	98 (58)	341 (56)			
Type of insulin regimen, n (%)						
Insulin Pump	44 (51)	74 (44)	266 (43)			
Multiple daily injections	29 (33)	76 (45)	241 (39)			
Conventional insulin*	12 (14)	15 (9)	78 (13)			
Basal insulin only	1(1)	0	6 (1)			
No insulin	1(1)	3 (2)	16 (3)			
Type of visit, n (%)						
Virtual	40 (46)	154 (92)	-			
Telephone	47 (54)	14 (8)	-			
Who attended the visit, n (%)						
Child only	4 (5)	40 (24)	-			
Family member only	17 (19)	13 (8)	-			
Both	66 (76)	115 (68)	-			

Who filled out the survey, n (%)			
Child/teen only	5 (6)	17 (10)	-
Family member only	69 (79)	134 (80)	-
Both	13 (15)	17 (10)	
Who attended from the diabetes team			
(%)			
Diabetes doctor	86 (99)	163 (97)	-
Diabetes nurse	30 (34)	113 (67)	-
Diabetes dietitian	4 (5)	96 (57)	7
Social worker	0	11 (7)	2
Local health care provider	6 (7)	20 (12)	

[†] Includes cystic fibrosis, monogenic diabetes, and Alstrom syndrome † Includes cystic fibrosis, monogenic diabetes, neonatal diabetes, post-pancreatomy diabetes, and medication induced diabetes

^{*} Conventional insulin: an intermediate-acting insulin at breakfast, a sliding scale of rapid-acting insulin for breakfast and dinner, and an intermediate- or long-acting insulin overnight.

Table 2. Effect estimate of usability for early and later pandemic periods

		Telepho	one	Virtual		
Model	Outcome	Effect Estimate (95% CI) †	p-value	Effect Estimate (95% CI) †	p-value	
	Usefulness Domain	-0.23 (-0.74, 0.27)	0.3419	0.18 (-0.11, 0.48)	0.2089	
	Ease of Use Domain	-0.24 (-0.62, 0.15)	0.2122	0.39 (0.17, 0.61)	0.0013	
Linear Mixed Effects Model	Interface Quality Domain	-0.22 (-0.70, 0.27)	0.3662	0.24 (-0.04, 0.52)	0.0894	
	Interaction Quality Domain	-0.07 (-0.51, 0.36)	0.7242	0.12 (-0.13, 0.37)	0.3394	
(Mean Difference)	Reliability Domain	0.20 (-0.39, 0.78)	0.4910	0.30 (-0.04, 0.64)	0.0804	
	Satisfaction Domain	-0.08 (-0.56, 0.41)	0.7502	0.28 (0.01, 0.55)	0.0450	
	Overall	-0.22 (-0.70, 0.27)	0.3578	0.25 (-0.03, 0.53)	0.0728	
Ordinal Logistic Mixed Effects Model	Future Preference [‡]	1.78 (0.11, 28.17)	0.6654	5.10 (1.02, 21.7)	0.0298	
(Odds Ratio)						

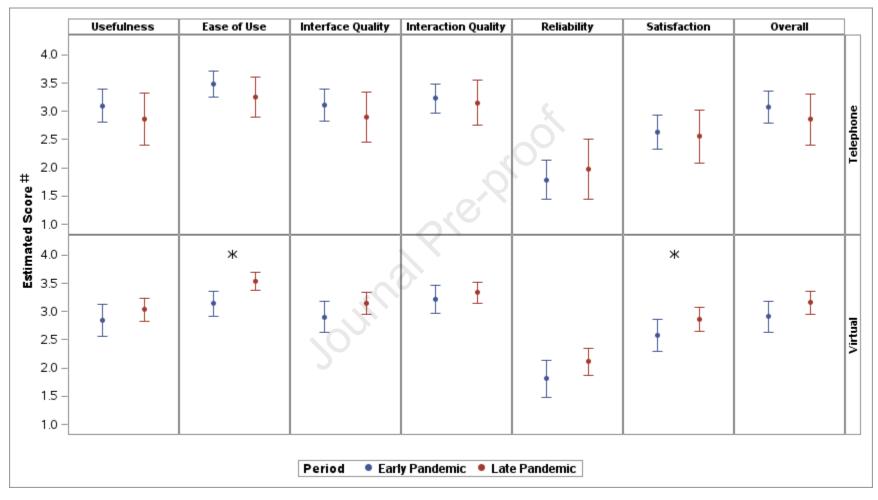
[†] The effect estimates for all outcomes comparing Later Pandemic vs. Early Pandemic periods, and calculated after adjustment for age, sex, time since diagnosis, pump use, CGM use, HbA1c, and distance from centre.

† For the outcome "Future Preferences", the cumulative probability of higher preference was modeled in the ordinal logistic mixed effects model.

Table 3. Thematic analysis of the benefits and disadvantages of telephone and virtual visits

Beneficial Aspects	Overall	Disadvantages O	
(n=129)	n (%)	(n=127)	n (%)
Less time consuming	94 (45)	Missed benefits of in-person interactions	47 (26)
Less missed school/work	30 (15)	Missed benefits of physical check ups	47 (23)
Convenience	19 (9)	Need for additional appointments (lab, supplies)	28 (14)
Saves money	16 (8)	Technology issues	14 (7)
Improved clinical care/support	14 (7)	Preference for in-clinic lab work	12 (6)

Figure 1. Estimated Telehealth Usability Questionnaire domain scores for early and later pandemic time periods, stratified by telephone and virtual visits



[#] Estimated mean scores and 95% CI, adjusted for age, sex, time since diagnosis, recent A1C, pump and sensor use, and distance from centre; * p<0.05

Appendix

Appendix A.1. Telehealth Questionnaire:

1. *Note: Please have an adult or child who participated in the recent diabetes visit fill out this survey. If a child/teen is filling out the survey, we would suggest an adult provide assistance if they are less than 13-years-old, and they may have assistance as needed from an adult if they are over 13 years-old*

The person filling out the survey is:

- a. A child or teen with diabetes
- b. A parent/family member/guardian of a child or teen with diabetes
- c. **BOTH** a parent/family member/guardian **AND** a child or teen with diabetes **TOGETHER**
- 2. Was your most recent diabetes visit planned to be by telephone (voice only) or virtual (by voice and video)?
 - a. Telephone (voice only, no video)
 - b. Virtual (visit was planned to have both voice and video)
- 3. From your family, who attended the most recent telephone or virtual visit with the Diabetes clinic?
 - a. Parent(s)/Family member(s)/guardian(s) only
 - b. Child only
 - c. Parent(s)/family member(s)/guardian(s) **AND** child
- 4. Who joined from your diabetes team? (select all that apply)
 - a. Diabetes doctor
 - b. Diabetes nurse
 - c. Diabetes dietitian
 - d. Social worker
 - e. Other health care provider(s) not from our Diabetes Team
 - f. Others (please specify):

Information about your most recent experience with a telephone or virtual visit

Please answer the following questions about **ONLY** the specific type of visit you had (**EITHER** telephone **OR** virtual (by video)). If you had a virtual visit, the term "virtual system" means either Skype for Business or Zoom.

- 5. Did having a telephone / virtual visit improve your access to healthcare services?
 - a. Not at all/Partly/Quite a bit/Completely

- 6. Did having a telephone / virtual visit save you time traveling to a hospital or specialist clinic?
 - a. Not at all/Partly/Quite a bit/Completely
- 7. Did the telephone / virtual visit provide for you/your child's healthcare needs?
 - a. Not at all/Partly/Quite a bit/Completely
- 8. Was it simple to have a telephone / virtual visit?
 - a. Not at all/Partly/Quite a bit/Completely
- 9. Was it easy to learn to use telephone / virtual system for the visit?
 - a. Not at all/Partly/Quite a bit/Completely
- 10. Was the telephone / virtual system pleasant to interact with?
 - a. Not at all/Partly/Quite a bit/Completely
- 11. Did you like using the telephone / virtual system?
 - a. Not at all/Partly/Quite a bit/Completely
- 12. Was the telephone / virtual system simple and easy to understand?
 - a. Not at all/Partly/Quite a bit/Completely
- 13. Was this telephone / virtual system able to do everything you would want it to be able to do?
 - a. Not at all/Partly/Quite a bit/Completely
- 14. Could you easily talk to the clinician using the telephone / virtual system?
 - a. Not at all/Partly/Quite a bit/Completely
- 15. Could you hear the clinician clearly using the telephone / virtual system?
 - a. Not at all/Partly/Quite a bit/Completely
- 16. Did you feel you were able to express yourself effectively?
 - a. Not at all/Partly/Quite a bit/Completely
- 17. When using the virtual system, could you see the clinician just as well as if you met in person? (*This question is removed from the telephone survey)

- a. Not at all/Partly/Quite a bit/Completely
- 18. Was the visit provided over the telephone / virtual system the same as an in-person visit?
 - a. Not at all/Partly/Quite a bit/Completely
- 19. Did you feel comfortable communicating with the clinician using the telephone / virtual system?
 - a. Not at all/Partly/Quite a bit/Completely
- 20. In general (not just during COVID-19), is the telephone / virtual system an acceptable way to receive healthcare services?
 - a. Not at all/ Partly/Quite a bit/Completely
- 21. In general (not just during COVID-19), would you choose to use telephone / virtual system services again?
 - a. Not at all/ Partly/Quite a bit/Completely
- 22. Overall, were you satisfied with this telephone / virtual system?
 - a. Not at all/ Partly/Quite a bit/Completely

Some questions specific to our diabetes program at BC Children's Hospital:

- 23. Which diabetes team members would you like to have involved in future telephone/virtual visits? (select all that apply)
 - a. Diabetes doctor
 - b. Diabetes nurse
 - c. Diabetes dietitian
 - d. Social worker
 - e. Other health care provider(s) not from BC Children's Hospital or Outreach
 - f. Others (please specify):
- 24. What makes it difficult for you/your family to use telephone/virtual care appointments (select all that apply)?
 - a. It's not difficult
 - b. I/we don't always have access to phone, Wi-Fi or a computer
 - c. I/we are not familiar with the technology
 - d. I/we don't have a quiet and private place where I can have a telephone/virtual visit
 - e. I/we don't feel this technology is safe and secure
 - f. I/we had trouble staying focused during a telephone/virtual visit
 - g. I/we find it hard to build a relationship by phone/virtually with my health care providers

- h. Other, please specify:
- 25. How long is your **TRAVEL TIME** to get to an **IN-PERSON** Diabetes Clinic visit?
 - a. Less than 30 minutes, one-way
 - b. Between 30 minutes and one hour, one-way
 - c. Between 1 and 2 hours, one-way
 - d. Between 2 and 4 hours, one-way
 - e. Between 4 and 6 hours, one-way
 - f. Between 6 and 8 hours, one-way
 - g. More than 8 hours, one-way
- 26. How many hours of school or work would be missed by the CHILD/TEEN travelling to the visit, if you had to come for an IN-PERSON visit with our Diabetes Clinic?
 - 0, 1, 2, 3, 4, 5-10, 10-15, 15-20, 20+, not relevant (scroll)
- 27. How many hours of school or work would be missed by the PARENT/GUARDIAN travelling to the visit, if you had to come for an IN-PERSON visit with our Diabetes Clinic?
 - 0, 1, 2, 3, 4, 5-10, 10-15, 15-20, 20+, not relevant (scroll)
- 28. How much money would your family spend, on average, if you had to come to an **IN-PERSON** visit with our Diabetes Clinic? (For example, expenses could include gas, transit fares, parking, child care, hotel, meals, etc.)
 - a. <50 dollars
 - b. 50-100 dollars
 - c. 100-200 dollars
 - d. 200-500 dollars
 - e. 500-1000 dollars
 - f. >1000 dollars
- 29. Please answer this question about **ONLY** the specific type of visit (telephone or virtual) you had: After the current COVID-19 pandemic is over, would you like to see telephone / virtual visits continued as a way for you to receive care from your diabetes team:
 - a. Yes, IN PLACE of ALL of my visits with the BC Children's diabetes team
 - b. Yes, IN PLACE of SOME of my visits with the BC Children's diabetes team
 - c. Yes, IN ADDTION to my BC Children's Hospital visits, so that I can be seen more often
 - d. No, I would prefer all of my visits to be in person
 - e. Unsure

30.		did you find most helpful about having your care at the Diabetes clinic done by telephone or virtually? COMMENT BOX (200 word limit)
31.		didn't you like about having your care at the Diabetes clinic done by telephone or virtually? COMMENT BOX (200 word limit)
32.	height	e aware that many families have difficulty reporting height and weight at telephone/ virtual visits. What makes it difficult to have home and weight measurements for a virtual visit? It is not difficult for me I don't have a scale or measuring tape I forget to do it I don't think it is useful for the visit I am worried about discussing my/my child's height and weight in these visits. Other:
33.	a.	It is not difficult for me I prefer measuring my A1C by finger-pokes at clinic. I forget to do it I don't think it is useful for the visit I am avoiding the lab because of fear of COVID-19 I / my child has a fear of having bloodwork done Other:
34.	physica a.	were to have many of your diabetes visits with us by telephone/ virtually, do you have a local doctor who could perform a regular al exam and measure height, weight, and blood pressure? Yes, I do No, I do not have a family doctor Other:
35.	a. b.	e addition of virtual / telephone care during the pandemic affected your well-being? It has made our diabetes care less stressful It has made our diabetes care neither more nor less stressful It has made our diabetes care more stressful

- 36. Diabetes Canada suggests children with diabetes should have 4 diabetes-related visits / per year. If you could have a combination of in-person and telephone/virtual visits with our team, **IN A FULL YEAR** how many diabetes related visits (including in-person, telephone, and virtual visits) **IN TOTAL** would you like to have with BC Children's Hospital diabetes clinic?
 - 1. __ (range 1-4)
- 37. Considering your answer to the above question:

IN A FULL YEAR, how many IN PERSON and TELPHONE/VIRTUAL visits you would like to have with our diabetes team:

- 1. In person: __ visits/year (range 0-4)
- 2. Telephone/virtual: __ visits/year (range 0-4)

Appendix A.2. Telehealth Usability Questionnaire, stratified by type of visit and early vs. later pandemic time period

Appendix A.2. Telehearth Osabinty Questionnane, stratified by ty	_	Telephone Visits Virtual Visits			Overall	
Usability Domain and Questionnaire Items	2020 Early pandemic (n=47)	2021 Later pandemic (n=14)	2020 Early pandemic (n=40)	2021 Later pandemic (n=154)	2020 Early pandem ic (n=87)	2021 Later pandemic (n=168)
Usefulness	3 (2-4)	3 (2-4)	3 (2-4)	3 (2-4)	3 (2-4)	3 (2-4)
A telephone/virtual visit improves my access to healthcare services	2 (2-3)	2 (2-3)	2 (2-3)	2 (2-3)	2 (2-3)	2 (2-3)
A telephone/virtual visit saves me time traveling to a hospital or specialist clinic	4 (3-4)	3.5 (3-4)	4 (3-4)	4 (4-4)	4 (3-4)	4 (3-4)
A telephone/virtual visit provides for my healthcare needs	3 (3-4)	3 (2-4)	3 (2-4)	3 (3-4)	4 (3-4)	3 (3-4)
Ease of Use and Learnability	4 (3-4)	4 (3-4)	3 (2-4)	4 (3-4)	4 (3-4)	4 (3-4)
It was simple to use this telephone/virtual system	4 (3-4)	3.5 (2-4)	3 (2-4)	4 (3-4)	4 (3-4)	4 (3-4)
It was easy to learn to use the system	4 (3-4)	4 (3-4)	3 (2-4)	4 (4-4)	4 (3-4)	4 (3-4)
Interface Quality	3 (3-4)	3 (3-4)	3 (2-4)	4 (3-4)	3 (2-4)	4 (3-4)
The way I interact with this telephone/virtual system is pleasant	4 (3-4)	3 (3-4)	3 (2-4)	4 (3-4)	3 (3-4)	4 (3-4)
I like using the system	3 (2-4)	3 (2-3)	3 (2-4)	3 (2-4)	3 (2-4)	3 (2-4)
The system is simple and easy to understand	4 (3-4)	4 (3-4)	3 (2-4)	4 (3-4)	4 (3-4)	4 (3-4)
This system is able to do everything I would want it to be able to	3 (2-4)	3 (2-3)	3 (2-4)	3 (2-4)	3 (2-4)	3 (2-4)
do						
Interaction Quality	3 (3-4)	3 (3,4)	4 (3-4)	4 (3-4)	4 (3-4)	4 (3-4)
I could easily talk to the clinician	3 (3-4)	3 (3-4)	3.5 (3-4)	4 (3-4)	3 (3-4)	4 (3-4)
I could hear the clinician clearly	4 (3-4)	3.5 (3-4)	4 (3-4)	4 (3-4)	4 (3-4)	4 (3-4)
I felt I was able to express myself effectively	3 (3-4)	3 (2-4)	4 (3-4)	4 (3-4)	4 (3-4)	4 (3-4)
I could see the clinician as well as if we met in person	-	-	3 (2-4)	3 (3-4)	3 (2-4)	3 (3-4)
Reliability	2 (1-3)	2 (2-3)	2 (1-3)	2 (2-3)	2 (1-3)	2 (2-3)
I think visits provided this way are the same as in-person visits	2 (1-3)	2 (2-3)	2 (1-3)	2 (2-3)	2 (1-3)	2 (2-3)
Satisfaction and Future Use	3 (2-4)	3 (2-3)	3 (2-4)	3 (2-4)	3 (2-4)	3 (2-4)

Overall Usability (all items)	3 (2-4)	3 (2-4)	3 (2-4)	4 (3-4)	3 (2-4)	4 (3-4)
Overall, I am satisfied with this type of visit	3 (3-4)	3 (2-3)	3 (2-4)	3 (3-4)	3 (2-4)	3 (3-4)
I would use these services again	2 (2-3)	2.5 (2-3)	2 (2-3)	3 (2-4)	2 (2-3)	3 (2-4)
The visit was an acceptable way to receive healthcare service	2 (2-3)	2 (2-3)	2 (2-3)	3 (2-4)	2 (2-3)	3 (2-4)
I felt comfortable communicating with the clinician during this visit	3 (3-4)	3 (3-4)	4 (3-4)	4 (3-4)	3 (3-4)	4 (3-4)

Likert scale: 1 = Not at all, 2 = Partly, 3 = Quite a bit, 4 = Completely; values are median (IQR)

Appendix A.3. Sensitivity analysis: Ordinal logistic mixed effects models for domain scores

		Teleph	one	Virtual		
Model	Outcome	Effect Estimate (95% CI)*	p-value	Effect Estimate (95% CI)*	p-value	
	Usefulness Domain	0.53 (0.15, 1.90)	0.3071	1.73 (0.80, 3.72)	0.1510	
	Ease of Use Domain	0.34 (0.05, 2.49)	0.2672	4.75 (1.22, 18.47)	0.0273	
Ordinal Logistic Mixed Effects Model	Interface Quality Domain	0.59 (0.16, 2.20)	0.4081	2.20 (0.74, 6.54)	0.1454	
(Odds Ratio)	Interaction Quality Domain	0.75 (0.21, 2.64)	0.6353	1.45 (0.60, 3.55)	0.3867	
(Odds Railo)	Reliability Domain	1.88 (0.49, 7.17)	0.3364	2.26 (0.83, 6.16)	0.1036	
	Satisfaction Domain	0.73 (0.17, 3.17)	0.6498	2.35 (1.08, 5.12)	0.0331	
	Overall	0.64 (0.13, 3.24)	0.5679	2.20 (0.86, 5.59)	0.0926	

^{*} The effect estimates for all outcomes were comparing Later Pandemic vs. Early Pandemic periods, and calculated after adjustment on Age at visit, sex, time since diagnosis, pump use, CGM use, HbA1c and distance from BCCH. # Among all outcomes of domain/overall scores, the cumulative probability of higher score was modeled in the ordinal logistic mixed effects model.

Appendix A.4. Family experience of telehealth diabetes visits: Select narrative comments

"What did you find most helpful about having your care at the diabetes clinic done by telephone or virtually"

45% of families noted that telephone/virtual visits were less time consuming and more efficient.

"A virtual visit is so much less time-consuming, and the time spent is specifically focused on the appointment itself. There is a lot of extra time spent commuting, parking, and waiting for the appointment with in-person visits."

Some also mentioned that having their care through telephone/virtual helped reduce interruptions and not having to miss school or work (15%). "I was working that time and just had to go on break for the virtual visit."

Telephone/virtual visits were also perceived as more convenient (9%), including convenience of doing the visit from home.

"My husband and I can both attend the appointments, as we can attend on our work breaks. It does not impact our workplace."

"My daughter didn't have to miss all day of school and we didn't have to spend all day for the appointment and travelling. We also didn't have to get up 5 AM to be on time for 9 AM appointment."

Cost-savings are another perceived benefit of telephone/virtual visits (8%) with some indicating that they saved on parking and travel costs (e.g., hotel, flights, ferry).

"It was helpful to not have to travel by plane, book hotels and find transportation in Vancouver. The cost is over \$3000 for one visit for us to travel with one child and one adult."

"What didn't you like about having your care at the diabetes clinic done by telephone or virtually"

Regarding perceived disadvantages of telephone/virtual visits, 26% of families noted that they missed the benefits of in-person interactions such as not making personal connections with the healthcare team and finding it harder to stay engaged.

- "For our son especially, we feel like he benefits from the in-person visits. There is just a different connection with people when you only see them virtually. Not sure if it is the same with other families but diabetes sucks at times. It made our son feel special coming in to see everyone. It is all about him and he really liked seeing everyone."
- "I find my son loses interest quite often and I do all the answering for him. Too much distraction at home."

Twenty three percent of the families also stated that they missed the benefits of physical checkup and were concerned that things may get missed compared to an in-person visit with a physical exam.

• "I worry that things might get missed such as the scar tissue that builds up on the stomach or the things that my son doesn't think to mention."

Some also indicated that telephone/virtual visits have caused additional visits for lab work or picking up supplies rather than all being completed during an in-person visit (14%).

• "It's also really convenient to have the A1c's done right there in the visit, but we can do that on our own time otherwise as needed."

Some of the families also noted having issues with technology including connection difficulties or issues with uploading data (7%).

- "Sometimes the audio would cut out, and I like the interaction between person to person better than online."
- "We weren't able to talk to the Doctor. No wifi where we were at the time meant we had to do a phone call. Couldn't add the doctor to the call. Was hard to hear all the questions."